

2007

The needs of Western Australian parents of children with an autism spectrum disorder, as influenced by the age of the child

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The Needs of Western Australian Parents of Children with an Autism Spectrum

Disorder, as Influenced by the Age of the Child.

Kerry Stedman

A report submitted in Partial Fulfilment of the Requirements for the Award of
Bachelor of Science (Psychology) Honours, Faculty of Computing, Health and
Science,

Edith Cowan University.

Submitted (August, 2007)

I declare that this written assignment is

my own work and does not include:

(I) material from published sources

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Declaration

I certify that this literature review and research project does not incorporate, without acknowledgement, any material previously submitted for a degree or diploma in any institution of higher education and that, to the best of my knowledge and belief, it does not contain any material previously published or written by another person except where due reference is made in the text.

Signature

Date 23 Jan 2008

Acknowledgements

To all the parents who wake up every day and look after these beautiful children, with all their challenges, I take my hat off to you and pray that in some way this research will assist in the process of alleviating your unmet needs. To all the parents who took time out of their busy lives to fill out the questionnaires, I thank you from the bottom of my heart.

Thank you to all the service providers who took part in this research, it would not have been possible without your help.

To my supervisor Eyal Gringart, thank you for all your wisdom, support and all the laughs over the past year. I am better equipped for whatever my professional career holds because of the time I have spent under your wing.

On a personal note I am grateful for all the answered prayers during this time and to all the people who have helped me along my journey. For friends who always know the right things to do and say and for their endless support when things get tough, thank you. For a brother who inadvertently, through his example, has always made me strive for my best and finally to the most amazingly generous, loving and supportive parents, thank you for everything, my achievements are a testament to you both.

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Running Header: IMPLICATIONS OF ASD ON PARENTING

Implications of parenting children with Autism Spectrum Disorders

Kerry Stedman

Implications of parenting children with Autism Spectrum Disorders.

Abstract

Autism Spectrum Disorders (ASD) impact upon parental stress levels above and beyond other childhood disorders. Nevertheless, little systematic research has been done on the perceived needs of parents of children with ASD. The literature has, however, reported that having a child with ASD impacts upon parental well being. These parents report increased levels of stress, depression, dysphoria, fear and marital difficulties as well as other problems. Although there is a debate in current research as to whether the age of the child with ASD affects parental well being, much of the body of knowledge suggests that different stressors and needs are experienced as a function of the developmental stage of the child. It can be concluded that more research needs to be conducted in order to establish effective means to assist these parents. The current paper reviews literature in the areas of diagnosis, prevalence, stress and well being. These topics are reviewed with an emphasis on parental experience. Gaps in the body of knowledge are investigated and further research directions are proposed.

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Submitted: 27 August 2007

Implications of parenting children with Autism Spectrum Disorders.

Intellectual disability has been a much neglected area of public health in Australia despite the demands it places on the community, the education system and families (Bower, Leonard, & Petterson, 2000). Although all forms of intellectual disability present such challenges to various extents, this review focuses on Autism Spectrum Disorders (ASD) due to their pervasive nature, increasing prevalence within the community (Bax, 1994; Croen, Grether, Hoogstrate, & Selvin, 2002) and the large impact they have on parental well being (e.g. Cashin, 2004; Dumas, Wolf, Fisman, & Culligan, 1991). Autism Spectrum Disorders include autism, Asperger's disorder, childhood disintegrative disorder, Rett's disorder and pervasive developmental disorder not otherwise specified (PDD-NOS) (American Psychiatric Association, Diagnostic Statistical Manual of Mental Disorders, 2000). Each of these disorders is characterised by impairments in interpersonal as well as communication skills and a restricted range of interest (*DSM-IV-TR*, 2000).

As previously documented, these unifying, pervasive and challenging characteristics can impede on the well being of affected families and more specifically the parents of children with ASD (e.g. Tobing, & Glenwick, 2002). In light of this, the current paper reviews literature on ASD in several distinct spheres and is divided into two parts. Part One includes Leo Kanners coining of the term autism in 1943; the *DSM-IV-TR* classification of ASD (otherwise known and described in the *DSM-IV-TR* as Pervasive Developmental Disorders); distinctions between ASD's; and diagnosis and associated difficulties and prevalence rates. These sections provide background on ASD and discuss the impact that having a child with ASD can exert on parental well being. Part Two further assesses the impact of ASD on parents' well being; how the age of the child with ASD impacts on parents' stress levels; why ASD has such a profound impact on parents; and the

impact and importance of support in assisting parents of children with ASD. The areas of well being and support are particularly pertinent, as research has shown that the interactions parents have with their disabled children can have a “profound impact on the child’s progress” (Lessenberry, & Rehfeldt, 2004, p1). Parent – child interactions impact social, cognitive and behavioural development (Gupta, & Singhal, 2005). Thus parents’ experiences, needs and stressors should be assessed to identify ways to facilitate the optimal outcomes of all family members.

Leo Kanner and the recognition of Autism

In 1943 Leo Kanner provided the first clinical description of what today is classified as autism (Kanner, 1943). It is of note, however, that children with this disorder may have previously been described as wild or feral (Simon, 1978). Kanner’s descriptions were grounded in developmental theory, and lead him to propose that early infantile autism was an “inborn, constitutional disorder” in which children lack motivation for social interaction (Volkmar, & Klin, 2005, p6; Kanner, 1943). In addition to the lack of motivation for social interaction, Kanner also observed profound impairment in the children’s ability to communicate. Out of the original study sample of eleven children, three were mute and all others presented with marked communication difficulties, including the presence of echolalia (Kanner, 1943). The term autism was coined by Kanner to name this combination of symptoms (Volkmar, & Klin, 2005).

Although many of Kanner’s observations and clinical descriptions are currently accepted, some aspects of his original theory have been refuted and revised by more recent research. One such revision is that although Kanner proposed that autism resulted from poor parenting, research since the 1960’s has found unequivocal evidence refuting this proposition (Volkmar, & Klin, 2005). Unfortunately, however, the stigmatisation of parents and the guilt many of them

experience still exists within our communities (Gray, 1994). Parents of children with ASD often perceive others as attributing the child's exceptional behaviours to their inadequate parenting skills (Gray, 1993), which in turn leads to feelings of frustration and social isolation (Benson, 2006; Gray, 1994; Gray, 1993). Thus, the experiences of parents of children with ASD are better appreciated with an awareness of the historical aspects of ASD, as Kanner's propositions, relating to causation, continue to impact upon parent stress, guilt and stigmatisation.

Diagnostic Statistical Manual (DSM)

Utilising Kanner's description of autism and the proceeding years of research, the *DSM-III* (1980) added the category of Pervasive Developmental Disorder to its Diagnostic Statistical Manual. This category was included to convey that individuals with autism and related disorders suffer impairment in similar, multiple areas of functioning. Although this term is widely accepted, other terms such as Autism Spectrum Disorder (ASD) are also commonly used to describe this cluster of disorders (Glasson, et al., 2005) and thus for the purpose of this review, these terms will be used synonymously.

The *DSM-IV-TR* clusters autism, Asperger's disorder, Rett's disorder, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (PDD-NOS) together due to their unifying symptoms of abnormal development of social interactions, impairment in communication and restricted and repetitive stereotyped behaviours (*DSM-IV-TR*, 2000). Children who meet the criteria for a diagnosis of ASD may also display a range of symptoms. These include hyperactivity, attention difficulties, impulsivity, aggression, self injurious behaviour, temper tantrums, abnormal responses to sensory stimuli as well as abnormalities in eating, mood, affect and fear (*DSM-IV-TR*, 2000). Their intellectual functioning ranges from severe mental retardation to superior intellectual

functioning, (American Academy of Pediatrics, 2001). Furthermore, children with ASD may demonstrate “islands of developmentally typical abilities” (p. 2) which often occur in areas such as puzzles, art, music and mathematics (American Academy of Pediatrics, 2001).

The unifying characteristics pertaining to these children’s social, behavioural and language development difficulties place significant strain on their parents. It is important to recognise the impact that these children’s symptoms may have on parental well being, particularly when these symptoms are severe (Siklos, & Kerns, 2006).

Brief Overview of Autism Spectrum Disorders

Whilst the above mentioned similarities, associated with social, behavioural and language development exist among ASD’s, the *DSM-IV-TR* classifies each of them separately. To allow for a greater understanding of both the similarities and differences between the disorders and thus the impact that each may have on parental well being, a brief summary follows.

For a diagnosis of autism, the child must present with difficulties relating to social abnormalities, impaired communication and a restricted range of interests and activities. Furthermore, onset must be prior to the age of three (*DSM-IV-TR*, 2000). Contrary to these diagnostic requirements for autism, the criteria for a diagnosis of Asperger’s disorder does not include impairment in communication and cognitive skills (*DSM-IV-TR*, 2000). The criteria does, however, require that the individual presents with significant impairment in their ability to engage in meaningful social interactions and they must have restricted, repetitive, stereotyped behaviours similar to those found in autism and other ASD’s (*DSM-IV-TR*, 2000). It is noteworthy that there is a debate as to whether Asperger’s disorder is a clearly definable disorder or

whether it is a case of high functioning autism (American Academy of Pediatrics, 2001) and the two terms are often used interchangeably.

Contrary to autism and Asperger's disorder, which are diagnosed more frequently in males than females at a ratio of 4:1 (Heidgerken, Geffken, Modi, & Frakey, 2005), Rett's disorder is a neurodegenerative disorder, which occurs almost exclusively in females. Onset is generally after one to two years of normal development and is characterised by a loss of hand skills and by the development of stereotyped hand movements, particularly hand wringing, loss of gross motor coordination, language impairments and hindered cognitive as well as social interaction skills (American Academy of Pediatrics, 2001; *DSM-IV-TR*, 2000).

Similar to Rett's disorder, is that of childhood disintegrative disorder, which is also characterised by a loss of skill after a period of normal development. In the case of childhood disintegrative disorder this degeneration of skills occurs after more than twenty four months of normal development. Although very rare, childhood disintegrative disorder shows a profound loss of language as well as social, play and motor skills (*DSM-IV-TR*, 2000; American Academy of Pediatrics, 2001).

The final disorder within the category of ASD is that of pervasive developmental disorder not otherwise specified (PDD-NOS). This disorder is characterised by a less stringent criteria than that utilised in the diagnosis of autism and includes those individuals who present with severe and pervasive impairment, but who do not meet the criteria for autism per se (American Psychiatric Association, 2000). Very young children may not present full symptomology due to their developmental stage and some individuals who are diagnosed with PDD-NOS may have their diagnosis changed to autism as they get older (American Academy of Pediatrics, 2001).

Whilst ASD's share common characteristics, it is evident that each presents its own challenges that may impede on parental well being in unique ways. In light of the spectrum nature of these disorders, diagnosis can be challenging, which further contributes to parental stress and the need for effective social support systems. Nevertheless, research into the experiences of parents of children with ASD's other than autism is lacking.

Age of and Difficulties Associated with the Diagnosis of Autism Spectrum Disorders

A clear diagnosis of children with ASD is paramount for their parents well being. This is because it provides clarity and recognises their eligibility for relevant support. Furthermore early detection is essential for the child's development (Howlin, 1997).

It is generally thought that ASD's are present from birth (Baghdadli, et al., 2002), even in the minority of cases where children display a normal course of development through infancy, followed by regression (Maestro, et al., 2005). It is also believed that the symptoms of ASD can be detected in children as young as twelve to eighteen months of age (Howlin, & Asgharian, 1999). With young children often presenting with deficits in symbolic play, joint attention, pointing gestures and social involvement (Baron-Cohen, et al., 1992).

Consistent with this, studies have found that, on average, parents of children with ASD notice abnormalities during the first two years of their child's life (Chawarska, et al., 2007; Baghdadli, et al., 2002; Bristol et al., 1996; Short, & Shopler, 1988). De Giacomo and Fombonne (1998) found that 30% of the 82 parents in their study noticed abnormalities prior to their child's first birthday, whilst 80% recognised abnormalities by the time the child reached the age of two. The leading cause for parental concern, in this study, was the child's delay in language development, followed by their abnormal social responsiveness, medical problems

and specific difficulties relating to sleeping, eating and attention (De Giacomo, & Frombonne, 1998).

Although such symptoms can to be recognised at the early age of twelve to eighteen months (Howlin, & Asgharian, 1999) and parents generally recognize abnormalities by twenty four months of age (Baghdadli, et al., 2002), research has suggested that diagnosis of ASD does not typically occur before approximately five to six years of age (Howlin, & Moore, 1997 as cited in Siklos, 2006). More detailed studies have, however, found that different ages of diagnosis occur as a function of the type of ASD present. Mandell, Novak, and Zubritsky's (2005) study of 969 caregivers for example, found that on average, children with autism were diagnosed by the age of 3.1 years, children with PDD-NOS were diagnosed by 3.9 years, whilst children with Asperger's disorder were diagnosed by the age of 7.2 years. This time delay in diagnosing Asperger's disorder may confound the average age of diagnosis for ASD and suggests that age of diagnosis should be viewed in relation to each specific disorder.

Whilst it can be seen that autism and PDD-NOS are generally diagnosed much earlier than Asperger's disorder (Mandell, et al., 2005), the diagnosis of these two disorders is still markedly delayed in relation to parents' identification of their child's difficulties. This delay in diagnosis has been attributed to several factors. These include the lack of biological markers for ASD (Gray, 1993), the large degree of variability that exists between individuals with ASD and the development of their symptoms, the scarcity of suitable assessment measures, the lack of specialised training among professionals and the shortage of specialised services (Chung, Smith, & Vostanis, 1995 as cited in Siklos, & Kerns, 2006). These delays are of particular importance, as early detection and treatment are paramount to the child's

development and for the parents' adaptation to having a child with a disability (American Academy of Paediatrics, 2001; Howlin, 1997).

Prevalence

A significant increase in the prevalence of ASD has been identified by clinicians, schools and service agencies worldwide (Bax, 1994; Croen, et al., 2002). For the majority of the history of autism, it was been considered a rare disorder, with prevalence estimates of 4:10 000. This prevalence rate has been identified as a large underestimation, with a current estimated prevalence of between 4-60:10 000 children depending on the "time, place, country and population from which the estimate is derived" (Prior, 2002, p 81). The British Medical Journal (2001), through analysis of all epidemiological studies up until 2000, estimated an average prevalence rate of 1:1000 for autism and 2.5:10 000 for Asperger's disorder.

Prevalence rates have been reported from two repeated population based studies in Sweden and France. The Swedish study found an increase in autism prevalence from 4.0:10 000 in 1980 to 7.6:10 000 in 1984 to 11.5:10 000 in 1988 (Gillberg, & Wing, 1999 as cited in Croen, et al., 2002). This increase was partially attributed to better detection of autism. This was supported by the French study, which concluded that when the method of identification was held constant, no increase in prevalence of autism was found (Fombonne, et al., 1997).

To further assess the impact of detection and diagnosis changes to the apparent increase in the prevalence of autism, a population based study was conducted in California. This study utilised eight successive birth cohorts, in which 6943 children were identified with autism. The results from this study indicated that during the study period of 1987-1994, prevalence rates for autism increased from 5.8 to 14.9:10 000, with a significant absolute change of 9.1:10 000 children. This increase was not influenced by "maternal age, race/ethnicity, education, child gender

or plurality” (Croen, et al., 2002, p 210). It is of note that during this period, the prevalence of mental retardation without autism decreased by an absolute change of 9.3:10 000, suggesting that improvements in detection and changes in diagnostic criteria have accounted for the increase in the prevalence of ASD’s. Whether a true increase in prevalence occurred during the study period is, however, unclear (Croen, et al., 2002).

The increase in prevalence reported by the above mentioned studies may be attributed to several non-medical factors (Prior, 2003). These include, changes to diagnostic practises, in which the criteria for diagnosis has be broadened to include the recognition of the spectrum nature of the disorder (Croen, et al., 2002; Prior, 2003). Furthermore, it is now more widely accepted that autism is sometimes associated with other neurodevelopmental conditions. Children who did not present with ‘pure’ autism were once excluded from prevalence data and their later inclusion may be a further contributing factor to the increase in reported prevalence. Other contributing factors include the heightened professional and public awareness of the disorder, which has not only increased the frequency of referrals but has also reduced the mean age at which assessment occurs (Croen, et al., 2002; Prior, 2003). Service provision has also increased markedly over the past decade, making diagnoses more readily available and clinicians more likely to reach a diagnosis of ASD. Hence a child with ASD may receive support, which was unavailable prior to these improvements (Prior, 2003).

Although the contributing factors of diagnostic changes and improvement in awareness and service provision do exist, no definitive answer can be given as to whether an increase in prevalence has actually occurred or if this increase is merely due to improvements in diagnosis and awareness (Chakrabarti, & Fombonne, 2001; Croen, et al., 2002; Prior, 2003). Nevertheless, current prevalence rates demonstrate

that ASD's are more common than once assumed (Croen, et al., 2002) and hence a significant number of parents are under the associated stress that these disorders pose.

Western Australian Data

The WA Register for Autism Spectrum Disorders was developed in 1999 and has collected data on new cases of ASD in Western Australia (WA) (Glasson, et al., 2005). The 2003 WA Register for Autism Spectrum Disorders Report noted that between January 1st 2003 and December 31st 2003, 218 people were diagnosed with an ASD in Western Australia. With the total diagnosed in the years of 1999 to 2002 being 159, 174, 213 and 216 respectively. Of the 218 cases in 2003, 84% had a diagnosis of autism, 12% had a diagnosis of PDD-NOS and 4% had a diagnosis of Asperger's disorder. No cases of childhood disintegrative disorder were reported (Glasson, et al., 2005). The age of diagnosis ranged from eighteen months to fifty years, with a median age of five years (Glasson, et al., 2005). Approximately "50% of cases were diagnosed by the age of five, 75% by the age of nine and 90% by the age of thirteen" (Glasson, et al., 2005, p5). Considerably more males than females were diagnosed, with a ratio of 5.5:1. This ratio is as expected due to the previously mentioned sex bias of ASD. Furthermore, the register recorded that 88% of the individuals diagnosed during the 2003 period had both parents of Caucasian origin, whilst 1% were of Indigenous Australian origin (Glasson, et al., 2005).

In a 2005 study the first Australian incidence figures for ASD's were reported. The study, which utilised data from the WA Register for Autism Spectrum Disorders calculated an annual WA incidence, in the zero to four year old bracket, of 5.5:10 000 for autism and 8.0:10 000 for autism, Asperger's disorder and PDD-NOS combined. An incidence, in the five to nine year old bracket, of 2.4:10 000 for autism and 3.5:10 000 for autism, Asperger's disorder and PDD-NOS combined and

an incidence, in the ten to fourteen year old bracket of 0.8:10 000 for autism and 1.4:10 000 for autism, Asperger's disorder and PDD-NOS combined. It is important to note that these figures are likely to be an underestimate, particularly in relation to Asperger's disorder and PDD-NOS. This is because children who have these disorders are less likely to access health care services and thus receive diagnosis. Furthermore due to the overlap of Asperger's disorder and autism the estimation of incidence for the sub-groups of ASD is also problematic (Williams, et al., 2005). The extent to which this affects incidence rates is unable to be established as no other WA incidence data is available. This suggests that the actual number of parents that experience the challenges of raising a child with ASD in the WA population is greater than that which is reported through the WA Register's Report.

The focus of the current paper will now turn to the stress and well being of parents of children with ASD. This is an important area, as gaining insight into the stressors and needs of parents of children with ASD may allow the identification of the supports that are needed to optimise outcomes for all family members.

Part 2

Stress and Well-being amongst Parents of Children with Autism Spectrum Disorders

Whilst studies consistently find that parents raising children with a disability experience more stress than parents of children who do not have a disability (Fisman, Wolf, & Noh, 1989), this is particularly true for parents of children with ASD. There is much research which supports the premise that ASD is particularly challenging for parents, with these studies consistently finding that parents of children with ASD experience more stress than parents of normally developing children (Fisman, et al., 1989) and children with other disabilities and chronic illnesses (e.g., Bouma, & Schweitzer, 1990; Dumas, et al., 1991; Kasari, & Sigman, 1997; Koegel, et al., 1992; Rodrigue, Morgan, & Geffken, 1992; Sanders, & Morgan, 1997; Tobing, &

Glenwick, 2002). Dumas, et al. (1991), for example, assessed parenting stress and dysphoria among parents of children with autism, Down syndrome, behavioural disorders and those with normal development. It was found that parents of children with autism experienced significantly and clinically higher levels of stress than parents of children with Down syndrome and those with normally developing children. Furthermore, mothers of children with autism presented with significantly and clinically higher levels of dysphoria than the parents of children with Down syndrome and those with normal development (Dumas, et al., 1991).

In a similar study (Sanders, & Morgan, 1997) parents of children with autism reported more family stress and adjustment difficulties than parents of children with Down syndrome and those with normally developing children. They also reported more stress associated with caring for their child and more stress relating to time demands and finding respite services (Sanders, & Morgan, 1997). This study also found that mothers of children with autism consistently reported child rearing as more stressful than the other groups (Sanders, & Morgan, 1997). In a comparable study, mothers of children with autism reported higher levels of stress and lower levels of parenting competency than parents with children who did not have a disability (Rodrigue, et al., 1990).

Other studies of parents of children with autism further support the deleterious impact that ASD's have on parental health and well being. During the initial diagnosis for example, it has been found that the reaction of many parents is similar to a grief response. Parent reactions often include shock, blame, guilt and anger (Gray, 1994; Gray, & Holden, 1992; Solomon, et al., 2001). These families often feel a sense of fear and isolation following the diagnosis of their child (Benson, 2006; Gray, 1994). Other impacting factors include the altering of the family's identity, structure, roles and the expected normal family life course (Nutik, & Yolles,

2005). Having a child with an ASD can significantly strain family resources (Salkever, 1985 as cited in Rogers, & Hogan, 2003) and the time allocated to leisure and other activities is also adversely affected (Rogers, & Hogan, 2003).

In a study that assessed 219 parents of children with autism, Sharpley and Bitsika (1997) reported that 80% of the parents were stretched to their limit and that the mothers had higher levels of stress than the fathers. Other studies have also reported such gender bias, with many of the behavioural aspects of children with autism adversely affecting the mothers' health to a greater extent than they affect the fathers' (Freeman, Perry, & Factor, 1991). Further, studies have also found that mothers report higher levels of depression and anxiety than fathers (Gray & Holden, 1992), with one study reporting that mothers tend to be the most severely affected members of the family (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). This gender difference has been partially attributed to mothers assuming greater responsibility for child rearing. They are also less likely to receive social support and respite from working outside of the home (Sharpley, & Bitsika, 1997).

Whilst studies have found that parents of children with autism express the need for more spousal support than parents of normally developing children (Konstantareas, & Homatidis, 1989), it was found that parenting a child with autism can have deleterious effects on marital intimacy, (Fisman, et al., 1989) satisfaction (Olsson, & Husang, 2002) and adjustment (Bristol, Gallagher, & Schopler, 1988). With some sources reporting that an estimated 80% of parents of children with autism separate (Drysdale, 2006).

Further examples of the deleterious effects of having a child with an ASD are found in a study that utilised a phenomenological approach. This study revealed that having a child with an ASD affected the parents' sense of self in a profound way (Cashin, 2004). Through interviews and focus groups parents expressed a loss of self

and of ease, they also expressed that they were less spontaneous due to their child's need for sameness, planning and structure, with this need for routine becoming incorporated into the self of the parent (Cashin, 2004). The parents also expressed that they had less social contact than they once had due to the challenges of taking their child out in public, the disruption to routine that socialising caused, the child's behavioural disturbances and the perceived judgements of other people within the community (Cashin, 2004).

The parents in Cashin (2004) also discussed having less material possessions due to the financial stress of having a child with an ASD and perhaps most profoundly, they expressed a loss of self. This loss of self encompassed the dominance of ASD in their lives and the little time and energy they had left for relationships and for individual pursuits. Many parents spoke of a 'loss of self entirely to autism' (Cashin, 2004, p. 167). The parents' sense of comfort was replaced with a constant sense of anxiety, exhaustion and hyper vigilance, with the child becoming central to all short and long term plans (Cashin, 2004). Whilst the parents in this particular study did speak of positives, such as connecting with their child and improved patience, these positives were tinged with sadness and were often mixed with frustration and exhaustion (Cashin, 2004). It was noted that these changes were not made consciously by the parents but rather reflected modifications that needed to be made for the parents' coping (Cashin, 2004).

The above mentioned studies all make evident that having a child with an ASD is stressful and poses more challenges and threats to well being than having a child who is otherwise challenged. Nevertheless, a focus group study of parents of adolescents with autism has reported that over time parents may gain a sense of coherence and control as their world views, values and priorities adjust and they begin to recognise and appreciate the contribution the child makes to the family and

the community (King, et al., 2006). It is important to note that this adaptation took time and that the researchers did make note of the impact and challenges of having a child with an ASD. Furthermore, the majority of the research in the area supports the difficult nature of parenting a child with an ASD.

Summing the impact that autism and other ASD's can have on parents, Gray (1993) has suggested that "fewer disorders pose a greater threat to the family than autism" (p. 1). Gray and Holden (1992) further postulated that "few disorders in children pose a greater threat to the psycho-social well-being of parents than autism" (p. 1). With these threats to well being manifested in terms of stress (e.g. Dumas, et al., 1991), marital problems (e.g. Olsson, & Husang, 2002), adjustment issues (Sanders, & Morgan, 1997), dysphoria (Dumas, et al., 1991) and a loss of self (Cashin, 2004).

Stress and Parental Well being as a function of the child's age

Whilst the above mentioned research make evident that having a child with an ASD is challenging, it is important to understand that as children's needs change with age so to do the needs of their parents (Rogers, & Hogan, 2003). It is of note that whilst each stage presents its own challenges, the disruptive nature of transition periods may also be a source of renewed stress, sorrow and apprehension, as parents reflect on what might have been (Nutik, & Yolles, 2005).

Various studies have assessed the differing roles and supports required during the child's developmental stages (e.g., Marcus, Kuncce, & Schopler, 2005), with the results of a ten year longitudinal study of families of children with autism in Australia ratifying the importance of considering the impact that these stages have on family stress levels and needs (Gray, 2002). These various studies suggest that during the child's early years the parents experience an intensely stressful period. During this period parents often deal with a number of stressful events including

grief over their child's dysfunction (Solomon, Pistrang, & Barker, 2001), fatigue due to their child's sleep difficulties (Marcus, et al., 2005), stress relating to the child's lack of communication skills (Gray, 1994), diagnosis hardships and stigma (Gray, 1993). During the early years, importance is placed on diagnosis, emotional support during the grieving process, parent training and counselling (Marcus, et al., 2005).

During the primary school years families of children with ASD experience a relatively relaxed period, particularly if adequate support and programs are provided by the child's school (Bebko, Konstantareas, & Springer, 1987). As the child develops cognitively and socially, behavioural difficulties often diminish (Marcus, et al., 2005), perceptions of stigma may reduce (Gray, 1993) and parents may redefine expectations of their child (King, et al., 2006). During the middle childhood years emphasis is placed on school, home-teacher relationships, learning problems and behaviour (Marcus, et al., 2005). It is noteworthy that whilst behavioural difficulties may diminish during this period, any violations of social norms are far less tolerated by the public as the child gets older (Gray, 1993).

The onset of adolescence typically ends the stable period of middle childhood, as the child develops both physically and sexually (Gray, 1993). Although Gray (2002) found improvements over time in parents psychological well being, he also reported parental depression and high levels of anxiety about the child's future. Whilst other studies have reported that during this period mothers of adolescents with autism are less likely to maintain their social support systems, self esteem and psychological stability and are less able to cope than mothers of adolescents with Down syndrome (Donovan, 1988).

Of further relevance to the discussion of parental stress, are those adolescents with ASD who become violent during this period (some become more placid). These individuals present particular problems, as families become more vulnerable to the

impact of the violence as the child grows physically (Gray, 2002) and their ability to restrain the adolescent is hindered. In these cases parental stress increases, whilst coping decreases (Gray, 1994). Furthermore, inappropriate sexual expression can also cause problems during adolescence as the child with autism matures sexually at the normal age, yet often is unable to express these desires appropriately. This can lead to many awkward situations that can be confronting to parents of adolescents with ASD (Gray, 1994).

The above mentioned research identifies difficulties that arise at different developmental stages and the corresponding needs of families. Nevertheless, there is disagreement among researchers. For example, whilst Dumas, et al. (1991) found no effect of child's age on mothers' stress and dysphoria levels, King et al. (2006) found that parental stress decreased linearly as the child grew older due to adaptation and gains to the parents sense of coherence and control (e.g. King, et al., 2006).

In summary, a number of the aforementioned studies report variation as a function of the child's age, in relation to the stress, well being and difficulties experienced by parents of children with ASD. Parents of young children with ASD often report grief, (Solomon, et al., 2001) fatigue (Marcus, et al., 2005) and diagnosis difficulties (Gray, 1993), whilst parents of primary school age children have reported a relatively relaxed period (Bebko, et al., 1987) where they redefine expectations (King, et al., 2006). Parents of adolescents with ASD have described a period of anxiety regarding the child's future (Gray, 2002) and their child's inappropriate sexual expression (Gray, 1994). Whilst studies dispute whether experiences of parents of children with ASD change as a function of the child's age (e.g. Dumas, et al., 1991), the results of all these studies confirm the stressful nature of ASD (Baxter, Cummin, & Polak, 1995) and the need for varying forms of social support for these parents.

The unique impact of Autism Spectrum Disorders on parents

As previously mentioned, children who have ASD can have a strong influence on their parents' well being and can be exceptionally difficult to deal with, no matter what their age (Gray, 1993). The existing research suggests that much of the stress parents of children with ASD experience is directly associated with the child's disability (Konstantareas, & Homatidis, 1991). Whilst problems with language are common and are reported as stressful, it is the behavioural characteristics of tantrums and obsessive, destructive, disruptive and anti social behaviours that are the cause of much distress (Gray, 1993; Gray, & Holden, 1992).

The delays and difficulties associated with obtaining a diagnosis for ASD also add considerable pressure to parents, as, although the symptoms manifest early in childhood, diagnosis can take several years and this can cause a period of considerable uncertainty and frustration (Gray, 1993). Diagnosis, as previously mentioned, is complicated by lack of biological markers, normal variance in child development and lack of experienced professionals. The frustration of diagnosis is further compounded by the limited services available for these children and their families once a diagnosis has been made (Gray, 1993) and the demands on time and resources that these services require once established (Gray, 1994).

Further stressful elements include the lack of public awareness in Australia regarding ASD which can lead to hostile and insensitive reactions from the public when these children behave inappropriately and violate social norms (Gray, 1993). These reactions are often exasperated by the child's normal physical appearance (Gray, & Holden, 1992). In a recent study of thirty two parents of children with autism many parents perceived themselves to be stigmatised and reported that one of the most unpleasant aspects of taking their child out in public was the way in which

their parenting skills were negatively judged. With this public criticism being both expressed and implied by the responses of individuals (Gray, 1993).

Further causes of distress for parents include that there is no cure for ASD and that although treatment may reduce some of the behavioural problems associated with the disorders, the children's potential for independence is questionable (Gray, & Holden, 1992). This concern and cause of distress was demonstrated in a study of fifty families in which it was established that parents of children with autism tended to exhibit a characteristic profile of stress relating to their child's future prospects. There was a general high level of concern regarding the child's well being once the parents were unable to care for them, a high level of concern regarding the child's future, their ability to function independently and their ability to be accepted into the community (Koegel, et al., 1992). These results suggest that having a child with an ASD presents very specific and stressful challenges (Koegel, et al., 1992). It is noteworthy that although these concerns are present throughout the child's lifespan, the stress associated with the child's independence may become heightened as the parents reflect on their own mortality and their inability to look after their child in the future (Sanders, & Morgan, 1997).

It can be concluded from the above mentioned research that there are numerous reasons why ASD has such a strong impact on parental well being. These reasons include the stress of coping with the behavioural, language and social characteristics of children with ASD (Benson, 2006), the difficulties associated with diagnosis, the availability of suitable treatment options (Gray, 1993), resource strain (Gray, 1994), lack of public awareness, stigma (Gray, 1993), the incurable nature of the disorders and worry about the child's future prospects (Gray, & Holden, 1992). These are all important to assess as it is these elements that should be addressed

through support and education, to assist parents of children with ASD and reduce the impact that these disorders have on them.

Support

The importance of support has been well documented (e.g., Siklos, & Kerns, 2006), with social support being a powerful predictor of adjustment (Gray, & Holden, 1992). This social support can be defined in relation to information that leads a person to “believe that they are cared for and loved, valued and esteemed and are important in a network of mutual obligation and communication” (Cobb, 1976, p. 300). This need for support is expressed by a father who wrote about his experience of having a son with autism.

I have experienced the fears and frustrations... the pain of mourning the child who is never going to be [and] that after the pain must come a celebration of the child who is. But I don't believe that parents can make this transition alone; they require information, help, support and encouragement. They need to know that others are dealing with the same challenges and they need to feel there is a national voice for parents in these situations.” (Autry, 1996, p. 14).

Amongst the pain, struggle and hope, this father voices the need for help, assistance and support.

When provided, support is seen to moderate negative outcomes such as depression, isolation and spousal difficulties for both parents (Dunn, et al., 2001; Gray & Holden, 1992). Furthermore, many studies have shown the positive impact of family supports such as respite services, home health care, family education, training and family counselling (Freedman, & Boyer, 2000). Additionally, adequate social support has been positively correlated with family adaptation (Freedman, & Boyer, 2000). The results of Bristol (1987) further endorse the importance of

support, in that “resources and parental beliefs were more predictive of adaptation than the severity of the child’s handicap” (p. 469).

Support groups have been recognised as important avenues for parents, in that, among other things, they encourage a sense of normality, belonging, empowerment and control over one’s environment (Solomon, et al., 2001). These support groups provide further benefits by:

promoting a psychological sense of community, providing emotional support, providing role models, conveying a powerful ideology, providing information, offering ideas about ways of coping, giving the opportunity to help others, providing social companionship, and promoting a sense of mastery and control (Solomon, et al., 2001, p. 114).

Solomon’s, et al. (2001) quantitative study found that the parents belonging to the support groups expressed a feeling of acceptance and being understood. They also reported feeling less alone and isolated and felt that they were no longer different. The groups also provided them with the opportunity to develop social networks in which they did not feel stigmatised. Furthermore, the parents reported positive personal change in the way they viewed themselves and their disabled child (Solomon, et al., 2001).

Further avenues of support for parents of children with ASD include parent education programs. It has been documented that parent education programs for parents of children with autism, have numerous positive effects. These include parents’ increased positive affect (Koegel, Bimbela, & Schreibman, 1996) and reduced stress (Moes, 1995). Furthermore, studies have found that following involvement in an educational program, mothers have reported decreases in depressive symptoms (Bristol, Gallagher, & Holt, 1993) and both parents have

reported increases in self efficacy (Feldman, & Werner, 2002; Wolfson, Lacks, & Futterman, 1992).

Although these support services in and of themselves provide assistance to parents, several studies have noted that it is the parents' beliefs about the adequacy of social support that predicts their adaptation to having a child with ASD (Bristol, 1984; Donovan, 1988). Bristol (1984) for example, found that the strongest indicator of healthy adaptation was the mother's perceived support from her spouse, whilst the parents' beliefs about the appropriateness of services for their child was also a strong indicator of the level of coping exhibited by the parents (Hastings, & Johnson, 2001). The perception of support has also been shown to decrease the impact of stress on maternal depression, further supporting the positive impact that social support can have on parental wellbeing (Wolf, Noh, Fisman, & Speechley, 1989).

Whilst the challenges and impact of parenting a child with ASD has been well documented and studies have confirmed that social support is advantageous to parental well being, very little attention has been paid to these parents' perceived psychological needs (Blackledge, & Hayes, 2006) and the extent to which these are met (Siklos, & Kerns, 2006). To assess this issue, Siklos and Kerns (2006) compared fifty six Canadian parents of children with autism and thirty two parents of children with Down syndrome. Whilst these two groups did not differ significantly in relation to the number of important needs reported, they did differ in relation to the types of supports they endorsed as important and unmet. This was indicated by the parents of children with autism reporting a greater need for consistent therapy for their children, as well as professionals who are knowledgeable about autism (Siklos, & Kerns, 2006). Only one third of parents of children with autism reported that their needs were met, reflecting inadequate social support provision by the service delivery system. Furthermore, whilst both groups reported a similar number of met

needs, the parents of children with ASD reported significantly less satisfaction with the help that they had received since diagnosis (Siklos, & Kerns, 2006). It was also noted that the parents whose children had marked behavioural difficulties, reported a greater number of important needs. This further ratifies that the stereotyped, ritualistic and odd behavioural symptoms of ASD may lead to poorer adjustment and the need for more social support (Siklos, & Kerns, 2006).

Summary

The unifying characteristics of impairment in social interactions, deficits in communication and restricted range of interests (*DSM-IV-TR*, 2000) make ASD's a particularly challenging cluster of developmental disorders. Since the first recognition of these characteristics (Kanner, 1943) to the present time, they have, at least in part been attributed to inadequate parenting. This has lead to stigmatisation and isolation and whilst recent research has refuted this attribution, it continues to affect parental well being. It is also important to understand the spectrum nature of this group of disorders in that the unique characteristics of each disorder and child may influence the parents' experiences in different ways. Research in this area is however unavailable.

The difficulties associated with the child's characteristics, diagnosis, stigma and isolation, place more stress on parents of children with ASD than on parents of normally developing children (Fisman, et al., 1989) and of children with other disabilities (e.g., Bouma, & Schweitzer, 1990). Parents of children with ASD exhibit higher levels of stress (Sanders, & Morgan, 1997), dysphoria (Dumas, et al., 1991) and describe feelings of guilt, grief, anger (e.g. Gray, 1994) and fear (e.g. Benson, 2006) They also describe having less time for social and recreational activities (Rogers, & Hogan, 2003). Parents of children with ASD describe a loss of self (Cashin, 2004) and changes to family identity, roles and structures (Nutik, & Yolles,

2005). Although reporting a higher need for spousal support (Konstantareas, & Homatidis, 1989) these parents tend to report marital problems relating to intimacy (Fisman, et al., 1989), satisfaction (Olsson, & Husang, 2002) and adjustment (Bristol, Gallagher, & Schopler, 1988).

The challenges and influences that ASD can pose for parents of children with ASD can be assessed in relation to the age of the child. Whilst the research is split regarding whether age of the child is influential to parental well being, results have suggested that different stressors, needs and supports may be required at different developmental stages. These include that during the child's early years, following diagnosis, parents often express grief (Solomon, et al., 2001) and fatigue, with parent training and counselling being a key area of support (Marcus, et al., 2005). During the primary school years some studies have suggested that stress is reduced (Bebko, Konstantareas, & Springer, 1987) with the focus turning to school, home-teacher relationships, behavioural problems and learning difficulties (Marcus, et al., 2005). The stable middle years of childhood are reportedly disturbed by adolescence, with difficulties relating to sexual development (Gray, 1993) and the child's future (Donovan, 1988) taking precedence during this stage.

Conclusion

The research reviewed makes evident that having a child with ASD poses specific challenges to parental well being and that support is vital to facilitate the optimal outcome of all family members. The body of knowledge is lacking in several key areas. There is little knowledge about differences in the experiences of parents in relation to each ASD. Such knowledge would allow for a deeper understanding of parental needs and for more comprehensive and tailored support services. Furthermore not enough is known about the impact of child age on parental stress and well being and on parents perceived needs and the extent to which these are

being met. Future research should address these gaps in knowledge. This will allow service providers to gain greater insight into the experiences of parents of children with ASD, their needs and the improvements needed. Such future research endeavours would inform practise, as well as policy makers toward the lives of parents of children with ASD.

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The Needs of Western Australian Parents of Children with an Autism Spectrum
Disorder, as Influenced by the Age of the Child.

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Abstract

Parents of children with Autism Spectrum Disorders (ASD) require significant support as they experience more stress than parents of children who are of normal development and those of children with other disabilities. Previous research has suggested that the experiences and consequent supports required by these parents may differ, as a function of the child's age. Little empirical research has assessed the perceived needs of parents of children with ASD. The current study utilised a modified version of the Family Needs Questionnaire (FNQ) to assess the needs of parents of children with ASD and the extent to which these needs were met. Ninety four parents completed the survey. The results showed that half of the needs on the FNQ were reported as unmet by these parents and that the needs of parents of children between the ages of 6 and 12 years were more frustrated than the needs of parents of children between the ages of 2 and 5 years. Implications for clinical practise, policy and future research are discussed.

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Submitted: 27 August 2007

The Needs of Western Australian Parents of Children with an Autism Spectrum Disorder, as Influenced by the Age of the Child.

Autism Spectrum Disorders (ASD) are a group of developmental disorders characterised by impairments in interpersonal and communication skills, as well as a restricted range of interests and stereotyped behaviours (American Psychiatric Association, Diagnostic Statistical Manual of Mental Disorders, 2000). This category of disorders includes autism, Asperger's disorder, childhood disintegrative disorder, Rett's disorder and pervasive developmental disorder not otherwise specified (PDD-NOS). The combination of characteristics individuals with these disorders exhibit can be particularly challenging and threaten family adaptation and health (eg. Cashin, 2004; Dumas, Wolf, Fisman, & Culligan, 1991). It is therefore important to assess family adaptation and need, particularly as the prevalence of ASD, in Australia, is currently estimated to range from 3.6 to 21.9:10 000 for 0-5 year olds, 9.6 to 40.8:10 000 for 6-12 year olds and 4.4 to 24.3:10 000 for 13-16 year olds (MacDermott, et al., 2007). These prevalence rates can be interpreted as indicating that this group of disorders influence an estimated half a million people in Australian families (Ford, 2007).

In light of these disorders having an influence on such a large number of Australian families and the impact that these children's characteristics have on parental well being, the aim of this study was to assess the perceived needs of parents of children with ASD and the influence that the child's age has on both perceived needs and the extent to which these are met.

Whilst ASD influences all members of the affected families, this is particularly true of the parents (e.g. Tobing, & Glenwick, 2002). Research suggests that parents of children with ASD experience more stress than parents of normally developing children (Fisman, Wolf, & Noh, 1989) and children with other

disabilities and chronic illnesses (e.g., Bouma, & Schweitzer, 1990; Dumas, et al., 1991; Kasari, & Sigman, 1997; Koegel, et al., 1992; Rodrigue, Morgan, & Geffken, 1992; Sanders, & Morgan, 1997; Tobing, & Glenwick, 2002). These studies have found that parents of children with ASD report more stress associated with caring for their child, time demands and finding respite services (Sanders, & Morgan, 1997). They also exhibit more adjustment difficulties than parents of children with Down syndrome and those with children of normal development (Sanders, & Morgan, 1997). Further, mothers of children with autism consistently find child rearing more stressful than the mothers of the previously mentioned groups (Sanders, & Morgan, 1997) and report lower levels of parenting competency than other parents (Rodrigue, et al., 1990).

Other studies have further ratified the deleterious influence that ASD can have on parental well being, with studies finding that the reaction of many parents to the diagnosis of ASD includes shock, blame, guilt, anger (Gray, 1994; Gray, & Holden, 1992; Solomon, Pistrang, & Barker, 2001) and fear (Benson, 2006). These parents often become isolated following the diagnosis of their child (Benson, 2006; Gray, 1994). Furthermore the identity, structure, roles and expected normal life course of the family is altered (Nutik, & Yolles, 2005) and significant strain is placed on resources (Salkever, 1985 as cited in Rogers, & Hogan, 2003) and time allocated to leisure and other activities (Roger, & Hogan, 2003).

Cashin (2004) found that parenting a child with ASD affected the parents' sense of self profoundly, with many parents speaking of a 'loss of self entirely to autism' (Cashin, 2004, p. 167). These parents reported a loss of ease and spontaneity and a constant sense of anxiety, exhaustion and hyper vigilance. They also reported less social contact due to the child's challenging behaviour, the child's need for routine and the perceived judgements of other people within the community (Cashin,

2004). The parents in this study expressed the lack of time and energy they had left for relationships and individual pursuits. They also reported less material possessions due to the financial stress of raising a child with ASD (Cashin, 2004).

It is of note that parenting a child with ASD seems to affect mother's health to a greater extent than it does father's (Freeman, Perry, & Factor, 1991), with research reporting higher levels of stress (Sharpley, & Bitsika, 1997), depression and anxiety (Gray, & Holden, 1992) in the mothers of these children, compared with the fathers. It has been reported that mothers are the most severely affected members of the family (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). In addition, the quality of the marital relationship is also influenced, in that parenting a child with ASD deleteriously affects marital intimacy (Fisman, et al., 1989), satisfaction (Olsson, & Husang, 2002) and adjustment (Bristol, Gallagher, & Schopler, 1988).

Although research has indicated that ASD influences parental wellbeing in numerous ways, little systematic research has assessed the influence of child age on this. The research which has been conducted suggests that different stressors and experiences may be had as a function of the child's developmental stage (Rogers, & Hogan, 2003). A ten year Australian longitudinal study emphasised the importance of assessing child age in the assessment of family stress and need (Gray, 2002). Results of this study suggested that most parents experience an improvement in their psychological well being and their social experiences as their child grows up. Numerous other studies have also found differences in light of the child's age (e.g., Marcus, Kunc, & Schopler, 2005).

The results of these studies suggest that the early years of the affected child's life are a period of intense stress for parents. Reasons for this include diagnosis difficulties, parental grief over the diagnosis (Solomon, et al., 2001), fatigue due to their child's sleep difficulties (Marcus, et al., 2005), stress relating to the child's lack

of communication skills and stigma (Gray, 1993, 1994). The needs of parents of children with ASD, during this period, include emotional support whilst grieving, parent training and counselling (Marcus, et al., 2005).

If parents receive adequate support from the child's school, they experience a relatively relaxed period during the middle years of childhood (Bebko, Konstantareas, & Springer, 1987). This can be attributed to the diminishing behavioural difficulties exhibited by these children as they develop both cognitively and socially (Marcus, et al., 2005). Furthermore, the parents' perception of stigma reduces (Gray, 1993) and they may redefine expectations of their child (King, et al., 2006). It is important to note, that whilst behavioural problems often diminish during the primary school years, any violation of social norms are far less tolerated by the public as the child grows older (Gray, 1993). Emphasis during these years is placed on school, home-teacher relationships, learning problems and behavioural issues (Marcus, et al., 2005).

Adolescence often disrupts the more relaxed period of middle childhood as the child develops both physically and sexually (Gray, 1993; Marcus, et al., 2005). This can lead to several problematic situations. These include that whilst the adolescent matures sexually at the appropriate age they are often unable to express these desires appropriately. This can lead to awkward and challenging situations for parents (Gray, 1994). Furthermore, parents of adolescents with ASD who become violent during this stage, are more vulnerable to the impact of this violence as they are less able to restrain the child. In these cases parental stress increases and their coping decreases (Gray, 2002). Parental fatigue is also reported during this stage (Marcus, Kuncie, & Schopler, 1997) and it is reported that mothers of adolescents with ASD are less likely to maintain social support systems, self esteem and their psychological stability (Donovan, 1988).

The aforementioned research identifies the differences in experiences and needs that may be felt as a function of the child's age. There is however disagreement amongst researchers as to whether the age of the child does affect parent well being and needs. For example, whilst Dumas, et al. (1991) found no effect of the child's age on mothers' stress and dysphoria levels, King, et al. (2006) found that parental stress decreased linearly and Gray (2002) suggested that parents' psychological well being improved as the child grew older. Nevertheless, the majority of research, including those mentioned thus far, confirm the stressful nature of parenting a child with ASD (eg. Baxter, Cummin, & Polak, 1995; Sanders, & Morgan, 1997; Sharpley, & Bitsika, 1997) and the need for varying forms of parental support (eg. Marcus, et al., 2005).

The importance of support has been well documented (e.g., McCubbin, & Patterson, 1983; Siklos, & Kerns, 2006), with social support being a powerful predictor of adjustment in families of children with ASD (Gray, & Holden, 1992). Although support can be defined in numerous ways, a definition previously utilised in the area of ASD, conveys a transmission of information that leads a person to "believe that they are cared for and loved, valued and esteemed and are important in a network of mutual obligation and communication" (Cobb, 1976, p. 300).

When support of this nature is provided, it has been demonstrated to moderate depression, isolation and marital difficulties in parents of children with ASD (Dunn, et al., 2001; Gray, & Holden, 1992). Similarly, adequate social support has been positively correlated with family adaptation (Freedman, & Boyer, 2000), with respite services, home health care, family education, training and family counselling positively impacting parental well being (Freedman, & Boyer, 2000).

Support groups for parents of children with ASD, have been found to positively impact upon parental well being, as they encourage a sense of normality,

belonging, empowerment and control over one's environment (Solomon, et al., 2001). Parents belonging to such groups have expressed a sense of feeling understood and being accepted. They also report less loneliness and isolation, with the groups providing opportunities for the development of social networks in which the parents do not feel stigmatised. Importantly, parents belonging to such groups have expressed positive personal changes to both the way they see themselves and their child with ASD (Solomon, et al., 2001).

Further avenues of support include education programs. These have been demonstrated to increase the positive affect of parents of children with ASD (Koegel, Bimbela, & Schreibman, 1996) and reduce their stress levels (Moes, 1995). Maternal depressive symptoms are reportedly reduced following involvement in such education programs (Bristol, Gallagher, & Holt, 1993) and both parents have reported increases in self efficacy (Feldman, & Werner, 2002; Wolfson, Lacks, & Futterman, 1992).

Although these support services in and of themselves provide important and necessary avenues of assistance for parents of children with ASD, several studies have noted that it is the parents' beliefs about the adequacy of social support that predicts their adaptation to having a child with ASD (Bristol, 1984; Donovan, 1988). With Bristol (1987) finding that "resources and parental beliefs were more predictive of adaptation than the severity of the child's handicap" (p. 469). Bristol (1984) further found that the strongest indicator of healthy adaptation was the mothers' perceived support from her spouse, whilst the parents' beliefs about the appropriateness of services for their child was also a strong indicator of the level of coping exhibited by the parents (Hastings, & Johnson, 2001). Furthermore perception of support has also been linked to maternal depression and well being (Wolf, Noh, Fisman, & Speechley, 1989).

Whilst the impact of parenting a child with ASD has been documented and studies have reported the positive influence of social support on well being and adaptation, very little attention has been paid to the parents' perception of needs (Blackledge, & Hayes, 2006) nor to the extent to which these needs are met (Siklos, & Kerns, 2006). A recent study, which assessed parents' perceived needs utilising a Canadian sample, found that parents of children with ASD and parents of children with Down syndrome differed in relation to the types of supports they endorsed as important and unmet. This was indicated by the parents of children with ASD reporting a greater need for consistent therapy for their children, as well as professionals who were knowledgeable about ASD (Siklos, & Kerns, 2006). Only one third of the parents of children with ASD reported that their needs were met, reflecting inadequate social support provision by the service delivery system. Furthermore, parents of children with ASD reported significantly less satisfaction with the help that they had received since diagnosis (Siklos, & Kerns, 2006).

The research discussed thus far identified the varying difficulties that may be experienced by parents of children with ASD as a function of the child's age and the different needs of parents during these stages. These needs vary in relation to whether they pertain mainly to the parent (parent centred) or to the child (child centred). In light of the differences researchers have found between parents of children of different ages and that the vast majority of research on parents of children with ASD suggests that the experience of these parents is more difficult than the experience of parents of children who are otherwise challenged, research in this area is warranted. In light of this, the current study advanced Gray's (2002) longitudinal approach through the means of a cross-sectional, quantitative analysis of the perceived needs and the need fulfilment of Western Australian parents of children with ASD, based on parent and child centred needs across varying child ages.

Aiming to advance Siklos and Kerns' (2006) research, the study utilised a modified FNQ to assess the overall needs of parents of children with ASD. Furthermore, the study examined the satisfaction of both important and less important needs, which is an addition to Siklos and Kerns who only considered the former. This is important because the degree to which a need is satisfied may influence its importance and unsatisfied needs may be viewed as more important simply because they are frustrated. The study also included an open ended question to allow respondents to add relevant information that was not covered by the items on the FNQ.

In light of the importance that parental perception of need and need satisfaction plays in moderating the challenging experiences of parenting a child with ASD (Bristol, 1984; Donovan, 1988; Hastings, & Johnson, 2001) and the lack of research into this (Blackledge, & Hayes, 2006; Siklos, & Kerns, 2006), it is timely and important to consult the parents of children with ASD. The research questions for this study were:

1. What are the needs of Western Australian parents of children with ASD?
2. To what extent are the needs of parents of children with ASD in Western Australia being met?
3. Are there significant differences in the number of reported child centred needs versus parent centred needs as a function of the child's age?
4. Are there significant differences in the satisfaction of reported child centred needs versus parent centred needs as a function of the child's age?

Method

Design

The study utilised a two way between subjects design with child's age (2-5 year olds and 6-12 year olds) as the independent variable. There were four dependent

variables (DVs): parent centred needs, child centred needs and the degrees to which each of these was satisfied. The FNQ provided measures of the four DVs.

Participants

Participants were recruited through a Perth ASD support group and through several service providers of behavioural therapy and speech pathology. To be included in the study the parents needed to have at least one child between the age of 2 and 18 years who had a diagnosis of an Autism Spectrum Disorder (autism, Asperger's disorder, PDD-NOS, Rett's disorder or childhood disintegrative disorder). The participant's mean age was 40.14 years ($SD = 6.4$) and ranged from 26 to 64 years of age, with the majority of respondents being female (88.78%). Furthermore it was ascertained that seventy two of the respondents had children with autism, six had children with Asperger's disorder, fifteen had children with pervasive developmental disorder not otherwise specified and one had a child with childhood disintegrative disorder. No respondents had children with Rett's disorder. Participation in the study was voluntary and no payment or reward was offered.

Materials

Materials comprised of questionnaire packs and reminder cards (see Appendix D). The packs included an information letter (see Appendix A), a Demographic Survey (see Appendix B) and the Family Needs Questionnaire (see Appendix C).

Demographic Survey

A nine item demographic survey was included to give background information and enable richer data analysis. Questions included those assessing age of the child, type of diagnosis, whether the family had multiple children with an ASD, whether the child/children with ASD had any siblings and the marital status of the parent/caregiver. (see Appendix B).

Family Needs Questionnaire

The Family Needs Questionnaire (FNQ) utilised in the study was initially developed to assess family needs and need fulfilment in parents and families of adults with Traumatic Brain Injury (TBI) (Kreutzer, 1988 as cited in Siklos & Kerns, 2006). The questionnaire was later modified for use within families of children with TBI and has been shown to have adequate reliability and validity to assess these family's perceived needs and the fulfilment of these (Serio, Kreutzer, & Witol, 1997).

Siklos and Kerns (2006) modified and utilised the FNQ in their investigation of the perceived needs of parents of children with autism. In accord with Siklos and Kerns, the FNQ that was utilised in the current study comprised of a 48-items likert scale questionnaire. This measured the importance of needs (1 = not important, 2 = slightly important, 3 = important, 4 = very important), and whether these needs are met (1 = yes, 2 = partly, 3 = no). Items on the questionnaire related to needs such as respite, financial support, education and family life. Siklos (personal communication, 29 March 2007) granted permission for the modified FNQ to be used in this study.

Furthermore, in order to facilitate the collection of a richer data set and to obtain relevant information that was not covered by the items of the FNQ, the questionnaire pack included an open-ended question. This asked: "Could you please list any other needs that you may have that were not covered in the questionnaire and indicate to what extent those needs are met?"

Procedure

Approval of the research ethics committee of the Faculty of Computing, Health and Science at Edith Cowan University was obtained. Following this, questionnaire packs were sent out to a large Western Australian parent support group and several service providers who had agreed to participate in the research.

Individuals within these services distributed the packs to parents of children with ASD who were on their registries. These packs included an information letter, which stated that returning the questionnaires was regarded as providing consent to participate in the research. The pack also included the demographic questionnaire, the FNQ and a reply paid envelope. To ensure confidentiality and minimise the risk of potential respondents concerns about communicating shortcomings of the service providers, the surveys were returned directly to the researcher. Furthermore, no identifying information was provided and thus all data were anonymous. Following the collection of the questionnaires the data was screened, entered and analysed using the Statistical Package for Social Sciences (SPSS) Version 14.

Results

Four hundred and thirty seven questionnaire packs were distributed to parents and 101 were returned, yielding a response rate of 23.11%. Of those returned, three were excluded because of missing demographic information. Only four questionnaires were returned from parents in age Group Three (ASD children of 13-18 year) and as this was not sufficient for analysis and group comparisons they were discarded.

Prior to analysis, all entries were examined for accuracy and missing data. Instances of missing data were sporadic and accounted for less than 1% of the overall responses. These data points were replaced by the mean of the relevant item, a conservative method recommended by Tabachnik and Fidell (2001). This method of addressing missing values was particularly conservative in the current study because reducing the variance in the respective items made it more difficult for significant differences to be detected by the analysis of variance that was used. Data screening was conducted on the remaining 94 questionnaires and all were deemed viable for analysis.

Respondents' answers were confined by the range of the likert scales and it was assumed that responses replicated real processes in the population sampled; hence no adjustments were made to univariate outliers. Multivariate outliers were assessed using Malahanobis distance with $p < .001$ and none were identified.

Descriptive statistics were produced to answer research question one, regarding the needs of Western Australian parents of children with ASD. Out of the forty eight questions on the FNQ, forty were reported as important or most important. Based on prior research (Siklos, & Kerns, 2006), needs that were rated as either important or most important were classified as "important." The mean of the scores on the top 10 important needs was above 3.7 out of 4 and these needs are presented in Table 1.

Insert Table 1 here

Descriptive statistics were produced to ascertain the parents' perception of their need satisfaction. This was conducted to answer research question two, regarding the extent to which the needs of parents of children with ASD in Western Australia are met. Based on prior research, needs were classified as "unmet" if they were rated as unmet or partly met (Siklos, & Kerns, 2006). In light of this, the results showed that half of the needs were rated as unmet. These perceived unmet needs are presented in Table 2.

Insert Table 2 here

As research questions two and three were distinct from each other, considering the association between the dependent variables (DVs), and as either

singularity or co-linearity were detected, each question was analysed by a separate MANOVA. The DVs of Child centred needs and parent centred needs related to research question three and were moderately ($r = .73$) correlated. The extent to which parent centred needs and child centred needs were met were strongly ($r = .83$) correlated.

A between subjects MANOVA was performed on the FNQ for the two dependent variables of child centred needs and parent centred needs. The independent variable was the age of the child (2-5 and 6-12).

SPSS was used for the analysis. The assumptions of MANOVA were met and alpha was set at .05

With the use of Pillai's Trace criterion, the combined DVs were not significantly affected by the age of the respondents' child, $F(2, 91) = 1.60, p > .05$. In other words, there was no significant difference in the number of important child centred needs and parent centred needs reported as a function of the child's age. Descriptive Statistics are presented in Table 3.

Insert Table 3 here

A between subjects MANOVA was performed on the FNQ for the two dependent variables of the extent to which parent centred needs were met and the extent to which child centred needs were met. The independent variable was the age of the child (2-5 and 6-12).

SPSS was used for the analysis. The assumptions of MANOVA were met and alpha was set at .05.

With the use of Pillai's Trace criterion, the combined DVs were significantly affected by the age of respondents' child, $F(2, 91) = 3.48, p < .05$. Univariate test

results showed that the extent to which parent centred needs were met was significantly affected by the age of the child, $F(1,92) = 4.21, p < .05$. Thus, the parent centred needs among parents with children in Group 2 (6-12 years) were significantly more frustrated than those of the parents in age Group 1 (2-5 years). Descriptive Statistics are presented in Table 4.

Insert Table 4 here

In response to the open ended question that asked the respondents to list needs that were not covered in the FNQ, respondents noted 66 additional needs. These frustrated needs centred on issues of funding, services, family life, public awareness, respite and education. The combination of funding and service provision equated to almost half of these needs.

In Group 1, thirty additional needs were reported, with these being grouped into seven different categories. Of the thirty additional needs, the most frequently reported related to the inadequacy of funding, with one third of these parents' additional needs relating to this area. In addition, one quarter of the responses related to inadequate service provision, with an additional quarter relating to issues surrounding family life. Further additional needs included those relating to public awareness, counselling, education and respite.

Group 2 reported thirty six additional needs, with these being more evenly spread across the seven categories of needs identified above. The most frequently reported additional needs related to services, with one quarter of responses relating to these. One sixth of responses related to funding issues, one sixth related to education, with the remaining additional needs relating to respite, issues surrounding family life, public awareness and mental health issues. Respite was noted as an

important additional need five times more in age Group 2 than in age Group 1 and educational issues were noted six times more in age Group 2 than in age Group 1.

Discussion

Research question one aimed to identify the needs of parents of children with ASD and the extent to which these needs are important. The results identified forty important needs, including those relating to teachers' knowledge, professional advice and financial support. Research question two aimed to assess the extent to which the parents' needs were met. Measured by the FNQ, the results showed that one third of the needs were frustrated. Research question three asked whether there was a difference in the number of child centred needs and parent centred needs as a function of the child's age. The results found no significant difference between the two age groups. Research question four concerned differences in the extent of satisfaction of parent centred and child centred needs as a function of the child's age. The results showed that needs of parents of children with ASD between the ages of six and 12 were significantly more frustrated compared with parents of children with ASD in the age group of two to five.

The number of important needs reported by the parents supports prior research that utilised the FNQ. Both the current study and Siklos and Kerns (2006) found that parents of children with ASD reported 40 of the 48 FNQ items as important. The current study found that half of the needs that are represented in the FNQ were reported as unmet by the Western Australian sample, whereas Siklos and Kerns (2006) found two thirds in their Canadian sample. These differences in perceived need satisfaction may be due to the inclusion of both important and less important needs in the current study's analysis of need satisfaction, as Siklos and Kerns only analysed the needs endorsed as important. The current study utilised all the responses to gauge satisfaction, because the importance of needs may be

influenced by the extent to which they are satisfied. The differences between the two studies may also be due to differences in service provision in Western Australia and Canada. The results of both the current study and those of Siklos and Kerns suggest that the service delivery systems in both countries are not adequately supportive of parents of children with ASD.

Whilst the number of important needs expressed by the parents in the two age groups did not differ significantly, the extent to which parent centred needs were met did. Parents in Group 2 reported significantly greater frustration of their needs than the parents in Group 1. This was contrary to prior research that suggested parents in Group 1 should have shown more needs and greater frustration due to issues of grief (Solomon, et al., 2001), fatigue (Marcus et al., 2005) stigma and diagnostic difficulties (Gray, 1993). Reconciling this discrepancy, Bebko, et al., (1987) reported that the primary school years are only more relaxed if there is adequate service provision. This suggests inadequate service provision for Group 2 in the current study. Furthermore it suggests that the needs of both the parents and children persist across the lifespan and that service provision should continue for children with lifelong disabilities, such as ASD, throughout the child's life rather than primarily focussing on early intervention. The current public health policy in Western Australia directs significantly greater resources toward the younger ages, with financial support and funded interventions ceasing once the child reaches six years of age.

The qualitative reports of a few parents in the current study were in accord with previous research (eg. Gray, 1993,1994; Solomon, et al., 2001) as they reported the early years of their children to have been more stressful. These comments included that "My time of most need was at time of diagnosis and the first one to two years after that. My responses would have been very different. Everything was very

difficult ... We are now able to relax.” Such comments were rare, however, and the majority of parents’ qualitative and quantitative responses reflected increased frustration during the children’s middle years.

The most frequently reported additional needs, across all respondents, were those of funding and service provision. In relation to funding, the quantitative data suggested that 82% of parents reported that their need for financial support was unmet and the qualitative data was congruent with this. The parents reported selling their cars and houses to pay for therapy. One mother wondered if she would have a house to live in when she was sixty. She stated that this depended on funding of therapy. Other parents have reported that they “work fifty to sixty hours a week to pay for therapy which makes them miss out on seeing their children grow up.” Furthermore, many parents reported the lack of government funding, with the money they receive being far less than that required for minimal therapy. This was strongly felt in age Group 2, where parents described that there was no funding for therapy for children over six. These comments all echoed that of a parent, who stated that they “are left alone by the government” and that “what parents really need is funding.” In light of research which suggests that resources “are more predictive of adaptation than the severity of the child’s handicap” (Bristol, 1987, p. 469) and that money impedes on all areas of the parents and the child’s life, this is particularly pertinent.

Service provision was another problematic area described by many of the parents. The comments related to the lack of therapists and services (both public and private) and to the services themselves. A parent from Group 1 commented on the public sectors’ lack of services, with the “government only offering one to two hours of untrained unprofessional services a week.” Parents spoke of waiting lists, with one mother suggesting that the wait is two years for some services. Parents also stated

the need for services closer to home, with one parent travelling two hours for one hour of therapy. Furthermore, the parents described the need for contact with other parents of children with ASD and for their other children to get support from siblings in similar situations. The research in this area suggests that providing such support, positively impacts upon well being, encourages a sense of normality, belonging and empowerment as well as reducing social isolation, loneliness, the effects of stigmatisation (Solomon, et al., 2001). These supports should therefore be made more readily available so as to allow positive personal changes in the parents and the way they see their children (Solomon, et al., 2001).

Information provision was also stated as lacking, with several parents commenting that they didn't know "where or how to obtain access to different services." One parent suggested that an ASD guide should be developed and provided to all parents of children with ASD so that they can make informed decisions. Such comments warrant the inclusion of more readily available and accessible parent education programs for these parents. Such education has been demonstrated to increase positive affect (Koegel, et al., 1996), reduce stress (Moe, 1995), decrease depression (Bristol, et al., 1993) and increase self efficacy (Feldman, & Werner, 2002) and are therefore an integral element in assisting these parents (Freedman, & Boyer, 2000).

Another key area of concern for parents of children with ASD is that of respite. The lack of respite and funding for such services was reported by many. One parent commented that "the biggest need we have as a family is getting respite time for our son." She further stated that "the lack of respite allocation and the financial costs not being sufficiently supported by the government leads to a high amount of stress in our household." Similarly other parents stated that the respite services available were not frequent enough, whilst others discussed the "virtually

impossible” nature of “sourcing a reputable person whom they feel comfortable with,” to provide such services. It is interesting to note that Group 2 reported the need for respite five times more frequently than parents in Group 1. Although this is again seemingly contradictory to research which suggests that the primary school years are a relatively relaxed period, the research does stipulate that this is only the case when adequate services are provided (Bebko, et al, 1987) Thus, the current high frequency of the reported need for respite suggests that the provision of these services is not adequate.

Another area of parental concern is that of the lack of public awareness regarding ASD. Comments made by these parents ratify Gray’s (1993) study into stigmatisation of parents of children with ASD. The parents in the current study commented that “people in society misinterpret behaviour as naughty and disruptive, they blame me for his behaviour because he appears normal.” This normal physical appearance and associated attributes of the child’s behaviour onto the parents, appears regularly in the research (eg. Cashin, 2004; Gray, & Holden, 1992) and is supported by the current study. Further needs in this area include educating the public, as one parent commented, “that society will never be educated enough on children with a disability and that makes it extremely hard for us to go out into society.” This lack of knowledge and the associated stigma associated with it is another area in need of funding and educational services.

Education was a key area of additional needs in Group 2, with this group of parents describing needs relating to education six times more frequently than parents in Group 1. This is as expected as parents in Group 1 do not have children of school age and therefore these needs may not yet be apparent to these parents. The parents in Group 2 described “their disappointment in the total lack of support from the school environment in terms of educational needs and delivery.” They also indicated

that mainstream education for children with ASD “needs much more resources, improvements, professional development for teachers (relating to ASD) and acceptance.” This particular parent echoed the sentiments that of many in her statement that “mainstream is a nightmare and that aide allocation and training is woeful.” Many parents described the lack of intervention strategies in place, particularly as the child grows older and that “inclusive education is not working at grass roots level.”

As support for parents of children with ASD is paramount to their well being and to the outcomes of their children (Siklos, & Kerns, 2006), the unmet needs reported above should be considered by relevant policy makers and service providers. Providing appropriate services to these parents will contribute to the parents’ welfare, will assist them in adapting to having a child/ren with ASD and will optimise children’s outcomes (Bristol, 1984; Donoyan, 1988).

Whilst the parents did provide the above additional needs, it is important to recognise that the FNQ had been utilised in a study which assessed the needs of parents of children with ASD in the past (Siklos, & Kerns, 2006) and that most of the ‘additional’ needs reported were actually covered in the FNQ. The FNQ has acceptable reliability and internal consistency (Siklos, & Kerns, 2006). Furthermore, the FNQ was deemed appropriate for use within the current study, as not only had it previously been modified for and utilised with parents of children with ASD (Siklos, & Kerns, 2006), but children with ASD and TBI often demonstrate similar cognitive, emotional and behavioural deficits. Parents of children with TBI and ASD report similar experiences of helplessness, denial, anger and guilt when the child is first diagnosed or injured (Gray, 1994; Gray, & Holden, 1992; Siklos, & Kerns, 2006; Solomon, et al., 2001). Further, both sets of parents fear that their children may

never reach independence (Lezak, 1988; Gray, 2002) and these parents coping and adaptation is a long term process.

The major limitation of this study was the lack of participants who had children in the third age group (those with children between 13 and 18 years). Adequate analysis of differences between age groups was hindered by the small number of participants in this group. The smaller number of participants who had children of an older age can be attributed to several reasons. The major reason for this was the sourcing of participants from intervention centres which fewer older children may utilise. This problem was largely unavoidable as when children grow up they utilise less intervention services and so their parents are therefore harder to contact within the community. Other reasons include the increase in diagnosis of ASD over the past couple of decades (Bax, 1994; Croen, et al., 2002). The influence of this on response rates is however expected to be minimal.

Martin (2000) suggested that a response rate of about 60% could be expected in general population samples. Whilst the response rate in the current study was 23.11%, it is in accord with other research into the experiences of parents of children with ASD. For example, Siklos and Kerns (2006) had a response rate of 20% and Sharpley and Bitsika (1997) had a response rate of 20.3%.

Future research should further assess the parents' perceived needs across the children's age groups, with particular focus on gaining data from parents of adolescent children. Furthermore, a nation wide study would allow the impact of differences in perceived experiences, due to varying funding and service provision, to be assessed and best practise to be determined at the national level. This current research should also be replicated post 2008 when new government funding for families of children with autism has been implemented. By conducting such research, after these changes have been made, data on the impact of these new

government provisions on perceived parental need satisfaction amongst Western Australian parents of children with ASD may be assessed. Future research should also look at including the above mentioned additional needs into the FNQ. This is particularly relevant for those relating to respite, as all other additional needs were covered in the FNQ. More questions relating to funding may also be warranted.

The current study makes a unique and significant contribution to research in the area of ASD, as no other Western Australian data on parents' perceived needs and the extent to which these are met is currently available. The current results suggest that only half of the needs covered on the FNQ are currently met, with some parents commenting that their needs are only met because "they are paying for it (services) themselves and had they been reliant on the government system their needs would certainly not be met." Furthermore the current results suggest that the needs of parents remain constant across the child's early to middle childhood and that parents of children in primary school have significantly more frustrated needs than parents of younger children. By allowing the parents an opportunity to provide such additional information, the current research gave voice to these parents, allowing them to feel consulted regarding their needs and the extent to which these are currently being met.

These findings have important clinical implications, as they provide information to clinicians who work with families of children with ASD, regarding the supports and services that these parents require. These services and supports are crucial to both the parents well being and the adaptation of the child (Freedman, & Boyer, 2000) and are currently not adequately provided in the Western Australian community. Furthermore, this research adds to the body of knowledge surrounding the challenging nature of parenting a child with ASD, that these parents require more support than is currently provided and that the needs of these parents are consistent

across the child's life and do not diminish as the child ages. These findings should be utilised to inform practice, as well as policy makers toward the life of parents of children with ASD.

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Appendix A – Information Letter

Dear Sir / Madam

My name is Kerry Stedman and I am conducting research into the needs of parents of children with autism as part of my Psychology Honours program at Edith Cowan University.

First and foremost thank you for taking the time to consider and possibly complete the attached questionnaires. I realise that your time is extremely precious and greatly appreciate your assistance.

If you choose to participate in this research you will be required to answer a demographic survey and a Family Needs Questionnaire, which will take about 15 minutes to complete. The questions will relate to your needs as a parent of a child with autism and how well you feel these needs are currently being met. These are important questions as they allow professionals in the area to gain a greater insight to the experiences and needs of families of children with autism.

Please be assured that if you choose to participate in this research the information that you give me will be kept confidential.

This project has been approved by the ethics committee of the Faculty of Computing, Health and Science at Edith Cowan University.

The findings of the study may be later available in published form but you will not be identifiable in any way.

If you have any questions or would like to discuss anything regarding this study, please call the Supervisor of this research Dr Eyal Gringart on (08) 6304 5631. If however you wish to talk to an independent person you may contact the fourth year coordinator Dr D McKillop on (08) 6304 5736.

If you feel discomfort completing the questionnaire and feel that you would like to speak to a professional you can contact Lifeline on 13 11 14 or alternatively you can contact Crisis Care on (08) 9223 1111.

Thank you again for your time and consideration of this research. If you wish to participate please fill in the questionnaires attached and return them via the supplied, reply paid envelope. Alternatively if the questionnaire is not attached to this information letter you may leave me a message on (*phone number to be advised*) and a questionnaire pack will be sent out to you shortly.

Kind Regards

Kerry Stedman

Appendix B – Demographics Questionnaire

- 1. Please circle: I am Female I am Male
- 2. What was your age in years at your last birthday? -----
- 3. What is your marital status?

Single (never married) Widowed Separated Divorced Defacto

Married
- 4. How many children do you have? -----
- 5. How old are your children? -----
- 6. How many children do you have with a diagnosed autism spectrum disorder?

- 7. What is the gender of your child/children who is/are diagnosed as having an Autism Spectrum Disorder?

Please circle: Male Female M F M F M F
- 8. How old is/are your child/children who is/are diagnosed as having an Autism Spectrum Disorder? -----
- 9. Where appropriate, is your child/children who is/are diagnosed with an Autism Spectrum Disorder attending primary or secondary school?

Please circle: Primary Secondary

Thank you for your time in filling out this questionnaire.

Please proceed to the next page for the Family Needs Questionnaire.

Appendix C – Family Needs Questionnaire

DIRECTIONS: The following statements describe needs that parents of children with developmental disorders sometimes have. Because many of these needs are likely to be important to you, please respond according to how important each need is in relation to your overall needs. Also, these needs normally change over time. We are interested in knowing how important they are to you at the present time and whether they are being met. The information you provide will help us to understand the needs of your family and other families of children with similar problems.

Please show how important you feel these needs are, relative to your overall needs, by using the scale below and placing a circle around the number which best describes your answer:

1	2	3	4
Least Important	Slightly Important	Important	Most Important

Use this scale to tell us whether each need is being met by circling: Y (Yes), P (Partly), or N (No):

Y	P	N
Yes	Partly	No

I NEED....	RELATIVE TO OVERALL NEEDS, HOW IMPORTANT? NEED MET?						
	1	2	3	4	Y	P	N
1. to be actively involved in my child's treatments and therapies.							
2. to be well-educated about my child's disorder in order to be an effective decision maker regarding the needs of my child.							
3. to have consistent physical therapy for my child.							
4. for professionals to be discreet when talking about my child while he/she is in the room.							
5. for my child to have friends of his/her own.							
6. to have different professionals agree on the best way to help my child.							
7. to be shown that my opinions are used in planning my child's treatment, therapies, or education.							
8. to have a professional to turn to for advice or services when my child needs help.							
9. to have help from other family members in taking care of my child.							
10. weekend and after-school activities for my developmentally delayed child.							

1	2	3	4	Y	P	N	
Least Important	Slightly Important	Important	Most Important	Yes	Partly	No	
I NEED....				RELATIVE TO OVERALL NEEDS, HOW IMPORTANT? NEED MET?			
11. to work with professionals who have expertise working with children who have the same developmental disorder as my child.	1	2	3	4	Y	P	N
12. to have consistent occupational therapy for my child.	1	2	3	4	Y	P	N
13. to be told why my child acts in ways that are different, difficult or unusual.	1	2	3	4	Y	P	N
14. to have time to spend alone with my other children.	1	2	3	4	Y	P	N
15. to be shown what to do when my child is acting unusually or is displaying difficult behaviours.	1	2	3	4	Y	P	N
16. to have information regarding my child's therapeutic or educational progress.	1	2	3	4	Y	P	N
17. to have help in deciding how much to let my child do by himself/herself.	1	2	3	4	Y	P	N
18. for my developmentally delayed child to have social activities other than with his/her own parents and siblings.	1	2	3	4	Y	P	N
19. to have help with housework.	1	2	3	4	Y	P	N
20. to have counselling for myself and my spouse/partner.	1	2	3	4	Y	P	N
21. to get enough rest or sleep.	1	2	3	4	Y	P	N
22. to get a break from my responsibilities.	1	2	3	4	Y	P	N
23. to spend time with my friends.	1	2	3	4	Y	P	N
24. to be told if I am making good decisions about my child.	1	2	3	4	Y	P	N
25. for the professionals working with my child to understand the needs of my child and my family.	1	2	3	4	Y	P	N
26. for my children's friends to feel comfortable around my child.	1	2	3	4	Y	P	N

1	2	3	4	Y	P	N	
Least Important	Slightly Important	Important	Most Important	Yes	Partly	No	
I NEED....				RELATIVE TO OVERALL NEEDS, HOW IMPORTANT? NEED MET?			
27. to have other family members understand my child's problems.	1	2	3	4	Y	P	N
28. to have my child's after-school friends to understand his/her problems.	1	2	3	4	Y	P	N
29. to have my child's teachers understand his/her problems.	1	2	3	4	Y	P	N
30. to discuss feelings about my child with a parent who has a child with the same disorder.	1	2	3	4	Y	P	N
31. to have my child's therapies continue throughout the summer months and school breaks.	1	2	3	4	Y	P	N
32. to be reassured that it is not uncommon to have negative feelings about my child's unusual behaviours.	1	2	3	4	Y	P	N
33. help dealing with my fears about my child's future.	1	2	3	4	Y	P	N
34. help in remaining hopeful about my child's future.	1	2	3	4	Y	P	N
35. to have my questions answered honestly.	1	2	3	4	Y	P	N
36. to be encouraged to ask for help.	1	2	3	4	Y	P	N
37. information about special programs and services available to my child and my family.	1	2	3	4	Y	P	N
38. to be shown respect by the professionals working with my child.	1	2	3	4	Y	P	N
39. financial support (e.g. from the government) in order to provide my child with his/her therapies, treatments, and care.	1	2	3	4	Y	P	N
40. the children in my child's classroom to understand that my child cannot help his/her unusual behaviours and difficulties.	1	2	3	4	Y	P	N
41. to have time to spend alone with my partner.	1	2	3	4	Y	P	N

1	2	3	4	Y	P	N
Least Important	Slightly Important	Important	Most Important	Yes	Partly	No

I NEED....

RELATIVE TO OVERALL
NEEDS, HOW IMPORTANT? NEED MET?

42. my child's school to set up a specialized education plan for my child.	1	2	3	4	Y	P	N
43. my child to have a teacher's aide with him/her at school who has knowledge about, or experience with, working with children with the same disorder as my child.	1	2	3	4	Y	P	N
44. to have the professionals working with my child to speak to me in terms I can understand.	1	2	3	4	Y	P	N
45. to have my spouse and me agree on decisions regarding our developmentally delayed child.	1	2	3	4	Y	P	N
46. my child's doctor and dentist to have experience working with children with the same disorder as my child.	1	2	3	4	Y	P	N
47. to go out for dinner with my family three times each week.	1	2	3	4	Y	P	N
48. to take week-long vacations by myself each year.	1	2	3	4	Y	P	N

49. Could you please list any other needs that you may have that were not covered in the questionnaire and indicate to what extent those needs are met?

Appendix D – Reminder Card

Recently a questionnaire asking about your family's needs, in relation to your child/children with an Autism Spectrum Disorder, was mailed to you.

If the questionnaire has already been completed, please accept our sincere thanks. If not, could it please be returned today? Because it was sent to a small representative sample of parents it is most important that your views are included in order for the study to be adequately representative.

If by some chance you did not receive the questionnaire or have mislaid it, please call me on 9403 0360 and I will send you another copy today.

Yours sincerely,

K. Stedman

Project Director

Table 1

Ten most frequently reported important needs.

Most Frequently Reported Needs	Mean
1. To have my child’s teachers understand his/her problems.	3.8661
2. To have a professional to turn to for advice or services when my child needs help	3.8283
3. To be well-educated about my child’s disorder in order to be an effective decision maker regarding the needs of my child.	3.8182
4. To have information regarding my child’s therapeutic or educational progress.	3.7879
5. To have my questions answered honestly.	3.7475
6. Financial support (e.g. from the government) in order to provide my child with his/her therapies, treatments, and care	3.7273
7. For the professionals working with my child to understand the needs of my child and my family.	3.7273
8. My child’s school to set up a specialized education plan for my child.	3.7243
9. To work with professionals who have expertise working with children who have the same developmental disorder as my child.	3.7172
10. My child to have a teacher’s aide with him/her at school who has knowledge about, or experience with, working with children with the same disorder as my child.	3.6735

Note. Higher scores denote greater importance of needs.

Table 2

The twenty four reported unmet needs in ascending order.

Unmet Needs	Mean
1. To take week-long vacations by myself each year.	2.5673
2. Financial support (e.g. from the government) in order to provide my child with his/her therapies, treatments, and care.	2.5657
3. My child’s doctor and dentist to have experience working with children with the same disorder as my child.	2.4898
4. Weekend and after-school activities for my developmentally delayed child.	2.4430
5. To have counselling for myself and my spouse/partner.	2.3919
6. To get a break from my responsibilities.	2.3879
7. To have help with housework.	2.3610
8. Help dealing with my fears about my child’s future.	2.3165
9. To have time to spend alone with my partner.	2.2858
10. To get enough rest or sleep.	2.2525
11. For my developmentally delayed child to have social activities other than with his/her own parents and siblings.	2.1977
12. To have consistent occupational therapy for my child.	2.1939
13. To spend time with my friends.	2.1835
14. For my child to have friends of his/her own.	2.1734
15. To have my child’s after-school friends to understand his/her problems.	2.1634
16. To have my child’s therapies continue throughout the summer months and school breaks.	2.1444

17. Information about special programs and services available to my child and my family.	2.1010
18. Help in remaining hopeful about my child's future.	2.0909
19. To have consistent physical therapy for my child.	2.0620
20. To have different professionals agree on the best way to help my child.	2.0618
<hr/>	
21. To have help from other family members in taking care of my child.	2.0614
22. To have time to spend alone with my other children.	2.0354
23. To be told if I am making good decisions about my child.	2.0202
24. To have other family members understand my child's problems.	2.0101
<hr/>	

Note. Higher scores denote greater frustration of needs

Table 3

Mean FNQ scores for the extent to which parent centred and child centred were deemed important.

<u>Child age</u>	<u>n</u>	<u>Parent centred needs</u>		<u>Child centred needs</u>	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
2-5	40	94.63	11.99	61.19	6.65
6-12	54	99.36	13.06	62.98	5.93

Note. Higher scores denote greater importance of needs.

Table 4

Mean FNQ scores for the extent to which parent centred and child centred needs were met.

<u>Child age</u>	<u>n</u>	<u>Parent centred needs met</u>		<u>Child centred needs met</u>	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
2-5	40	56.39	9.50	35.44	6.27
6-12	54	61.07	12.07	36.57	7.69

Note. Higher scores denote greater frustration of needs

Instructions for Authors:

Publication. The *International Journal of Disability, Development and Education* (IJDDDE) is published four times per year by Routledge, Taylor & Francis group, Informa UK Limited. IJDDDE also publishes book reviews written at the invitation of the Book Review Editor.

Articles. The Editor invites articles for consideration concerned with all aspects of theory, research, and practice in the areas of disability, human development, and education. Research, review, and issues oriented articles will be considered as will descriptions or cross-cultural comparisons of education, special education, and rehabilitation in developed and developing countries. Articles of 5,000 to 7,000 words would be considered a typical length and should be accompanied by up to a maximum of six keywords, to assist indexing and subsequent online article retrieval. Brief reports (3,000 to 4,000 words) will also be considered for inclusion in the Journal.

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All submissions should be made online at the *International Journal of Disability, Development, and Education's Manuscript Central site*. New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre.

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Terminology. IJDDDE uses *people first* language. The general form *person with a disability* is used rather than *disabled person*, so descriptions such as a *student with cerebral palsy* are acceptable. As *normal* has multiple meanings, more precise terms such as *children without a hearing impairment* should be used. Generic descriptions such as *students*, *participants*, and *adults* are preferred to the term *subjects*. IJDDDE uses the term *intellectual disability* rather than *mental retardation* or *learning disability*.

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